

Disability and income transfer in relation to congenital Zika syndrome: a study of provisional measure 894/2019

Deficiência e transferência de renda diante da síndrome congênita do *Zika* vírus: um estudo sobre a Medida Provisória 894/2019 (resumo: p. 15)

Discapacidad y transferencia de renta ante el síndrome congénito del zika virus: un estudio sobre la medida provisional 894/2019 (resumen: p. 15)

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Since 2015, Congenital Zika Syndrome (CZS) has been a feature of the Brazilian context and has moved beyond public health to demands for social protection. Given the intersection between poverty, disability and the social security framework, we examine Provisional Measure 894, which provides a lifetime monthly income for affected children. We conduct a qualitative study, analysing public documents and reviewing the literature, in order to discuss this instrument in the light of social security frameworks for unconditional cash transfers for People with Disabilities (PwD) in Brazil. State responses did not have an impact on income insufficiencies, since they were initially intended to respond to emergency situations and referred to pre-existing policies; this culminated in an income transfer modality, the Continuous Cash Benefit, being replaced by a Lifetime Pension, demonstrating a weakening of comprehensive social protection.

Keywords: Disability. Social protection. Congenital zika syndrome



Introduction

Since 2015, a new generation of children with disabilities has led to concerns about public policies related to Congenital Zika Syndrome (CZS). The extent of the epidemic transcends Public Health, requiring social protection activities linked to child development and reparation for the historical dismantling of the rights of People with Disabilities (PwD).

CZS emerged within a national context of political and economic turbulence, related to the minimal State and the retraction of the legacy of social rights, in line with trends for global economic neoliberalism which support “measures for the deregulation of labour and the expropriation of public social protection mechanisms”¹ (p. 170).

Since 2016, state Social Protection responses have focused on social welfare benefits already provided for within the regulatory framework, with an emphasis on the Continuous Cash Benefit (BPC), an unconditional cash transfer modality aimed at people in extreme poverty. However, in 2019, Provisional Measure (MP) 894² emerged, replacing the BPC with a special lifetime pension for children with Zika-associated microcephaly, born at the peak of the epidemic.

This article examines the features of the state response set out in MP 894/2019. The aim is to discuss this instrument in the light of social security frameworks for unconditional cash transfers for PwD in Brazil.

We studied scientific publications, and national and international public documents for a qualitative study of socio-economic indicators in CZS. We conducted a thematic content analysis of MP 894/2019 and of correlated public documents, identifying the shape of the state response to income transfer.

We discuss the social construction of disability and social security, which express State action in the face of structural inequalities. We address the socio-economic impacts of CZS and the relationship between disability and poverty. We also present an analysis of MP 894/2019 and of related regulatory instruments, outlining state responses.

Brazilian State action in relation to income transfer and the CZS scenario provides a platform for debate about improvements to or the worsening of contradictions and gaps in the rights of PwD.

Disability and social security frameworks

In contemporary times, disability is understood as a social relationship that provides a purposeful agenda and gains within the field of rights^{3,4}. However, disability was constructed through discourse and practices based on an evaluative rationality between normal bodies and deviant ones, on the binary logic of capacity and incapacity that resulted in the subordination of PwD⁵⁻⁷ which persists to this day.



In Antiquity and the Middle Ages forms for the annihilation of PwD occurred through negligence or abandonment, as well as legalized extermination^{5,8,9}. In modern times, an understanding of poverty as a useful educational condition for discipline at work and acceptance of authority¹⁰ contributed to the establishment of hygiene, eugenic and moralistic policies and practices, which shaped bodies and behaviour⁵. The State and other dominant sectors, such as the church, enacted incarceration procedures, and constituted power and knowledge capable of classifying, naming and controlling PwD and anyone else who represented a threat to the instituted order through their departure from the established norm^{5,8}.

The capacity/incapacity binary became more intense as social structures were erected on the notion of healthy and skilled bodies for sale within the labour force. With the development of the capitalist mode of production, disability expressed the impossibility of a productive life, given the centrality of labour in the capacity/incapacity relationship.

From the second half of the 19th century, the contributory model of Social Security funded by workers and regulated by the State emerged as a response to risks of interruption to the capacity to work¹¹. During the 20th century, Social Security became the central component of the Welfare State “and was a determinant in the regulation of economic and social relationships”¹² (p. 324). In the 1940s, the universalization of social services and a minimum wage for non-contributors was established in Europe as a form of managing inequality, maintaining the primacy of the condition of productive labourer contributing to the condition of the citizen^{13,14}, while contradictorily making the State responsible for the provision of basic needs as a social right.

It was only in the 1980s that the Social Security perspective of citizens’ rights was adopted in Brazil. The BPC was the first comprehensive social protection framework^{15,16} in the form of an unconditional and non-contributory cash transfer for PwD and the elderly living in extreme poverty. To access this, PwD had to fulfil *per capita* income criteria of below one quarter of a minimum wage and a functioning status that made work impossible. The BPC, to the value of one minimum wage, is neither transferable nor lifelong, since it requires periodic reassessment of beneficiary functioning and income.

The BPC guarantees the Right to Life in conditions of extreme poverty¹⁷, but expresses the capacity/incapacity binary through its functioning criteria which do not take historical exclusion from work into account, and through its focus on basic needs, providing an extremely low income cut-off point that excludes PwD also affected by poverty. It reaches the vulnerable, providing for the consumption of goods and basic services, but does not fill the gap of income provision¹⁸, particularly when we consider that the daily care of PwD, particularly children, prohibits the exercise of labour of at least one member of the family, usually a woman.

Although the BPC represents an important advance in the field of rights, PwD experience structural exclusion and restrictions to participation that determine and condition poverty, meaning that comprehensive social protection needs to be strengthened. However, the neoliberal political and economic agenda has a different logic, one that has led to reversals to quality protection as a social right¹³.



CZS and the relationship between disability and poverty

The vertiginous increase in cases of children with microcephaly and other conditions associated with the Zika virus was predominantly seen in the northeast region^{19,20}, one of the most impoverished and deprived in Brazil. The highest prevalence occurred in low socio-economic areas, with a possible association with maternal protein malnutrition²¹. These facts locate CZS within a more general scenario of the relationship between disability and poverty.

Despite the restricted literature about the economic impact on families²², studies including socio-economic variables reveal the predominance of family incomes up to two minimum wages, provider unemployment or informal labour, young mothers and fathers, as well as residence in locations with precarious sanitation and access to services²³⁻²⁹.

Insufficient income is one of the main causes and expressions of poverty, although this does not expose the multidimensionality and complexity of this phenomenon. Proposing a multidimensional approach to poverty, Sen³⁰ suggests a life context in which a lack of basic service provision, the denial of political rights, the existence of disability and other factors foster social vulnerability.

The World Disability Report (WDR) addresses the conditions of poverty and privation that affect PwD, highlighting a scarcity of financial resources and the absence of or precarious access to social policies in the majority of countries around the globe³¹. Barnes and Sheldon³² consider a broad concept of poverty in relation to disability and discuss the intersection with other conditions that foster risk and vulnerability, such as gender and ethnicity. The authors assert that PwD are the poorest of the poor and suggest that neoliberal economic prescriptions particularly affect PwD, given the tendency of the State to become less accountable through redistributive social protection policies

Since it affects early childhood, the CZS “feedback loop”³³ (p. 235), through which PwD remain within the most impoverished social strata, is even more critical. In childhood this loop is bidirectional, since 43% of children under five years old who live in low income countries are at risk of not achieving their full development³⁴ while, at the same time, poverty is “more severe and, proportionately more frequent where the presence of children with disability is noted”³⁵ (p.201)^(e).

Pinto et al.³⁶ demonstrate a negative variation of over 100% of income in families with children and adolescents with rare and complex health conditions – cystic fibrosis, mucopolysaccharidoses and osteogenesis imperfecta. Expenditure aimed at meeting needs arising from these health conditions are considered catastrophic - between 12% and 31% of income.

In a 2017 study³⁷, the United Nations Development Programme (UNDP) demonstrated that the Zika epidemic has both direct and indirect long-term and high-cost impacts for countries, with more profound ramifications for the poorest regions. Incidence of CZS implies loss of productivity due to the morbidity and premature mortality of those affected, and to the fact that those responsible for direct care drop out of the workforce, which is related to the issue of gender, since women are more involved in the reproductive work connected to care.

^(e)Based on 2010 data from the Brazilian Institute of Geography and Statistics (IBGE), França³⁵ suggests that the percentage of households experiencing financial poverty by PwD age is 73.9 for those aged zero to five years and 73.6 for those aged six to 14 years. For other age groups, these percentages fall: 45.2 (15 to 64) and 15.4 (65 years or above).



Cabral et al.²⁵ identify a predominance of single and unemployed women, as mothers of children affected by CZS in Sergipe. The Duarte et al.²³ study about the needs of the children affected notes that

There is a difficulty in dealing with financial issues, given that care is expensive and, in most cases, it is necessary for at least one member of the family to stop working to care for the child, since it is rare for families to be able to pay someone to help and the mother therefore becomes the main carer²³. (p.254)

Colón-Gonzales et al.³⁸ estimate the economic burden of the neurological sequelae related to the 2015/2016 Zika epidemic at two billion dollars a year in Latin America and the Caribbean. For the specific CZS group, the UNPD³⁷ asserts that indirect costs related to loss of income due to childcare obligations, where there is a high rate of Zika transmission, are estimated at around four hundred million dollars for the region.

To calculate direct medical costs, the UNDP³⁷ adopts non-medical cost components, including loss of productivity due to higher morbidity and premature mortality and loss of productivity due to one parent dropping out of the workforce. Thus, over a lifetime the estimated cost of CZS is 0.89 million dollars per case and 1,707 dollars per case per month (six times higher than the Brazilian minimum wage).

The UNDP³⁷ asserts that existing cash transfer programmes in Latin America are not sufficient to guarantee the support required by children and their families to lift them out of vulnerability and demands:

financial assistance proportional to the real cost of care, as well as subsistence opportunities for mothers at risk of permanently leaving the labour market³⁷. (p.10)

Provisional Measure (MP) 894/2019 and its antecedents: responses in three acts

An MP is an instrument that has pragmatic implications because of its immediate effect and political ramifications for the mobilization of debates and coalitions around its subject, since it requires approval by the National Congress within a specific timeframe^(f). At the same time, it refers to previous legislative acts or voids, and is not therefore an isolated action, but rather part of a process of construction related to a public issue that involves multiple agents and interests in dispute.

MP 894 of 4 September 2019² established a special pension for children with microcephaly arising from Zika, born between 1 January 2015 and 31 December 2018, who are beneficiaries of the BPC. The instrument converted a cash transfer modality, the BPC, into a special pension, with the difference being that this is for life. There was no direct effect on the expected financial impact of CZS, given that it was aimed at the same children who already received the BPC, with no additional value or increase in access arising from new criteria.

^(f) MPs are regulatory acts with the force of law issued by the executive branch for urgent and relevant cases with immediate effect. Their provisional nature arises from a validity period of up to one hundred and twenty days (sixty initial days that can be extended once for the same period) to be processed in the National Congress so as to be approved in full or with amendments, initially becoming a Conversion Bill subject to a vote and then becoming law¹⁸.



Although the issue was treated as a priority, there were no innovations to address the BPC's historic contradictions, for example the institution of the PwD as the recipient of the benefit and of the family as the nucleus for ascertaining income, which has a significant impact on the family's daily life, particularly on that of mothers, who tend to give up any financial gains or rights in order to remain within the benefit's cut-off limit³⁹.

The need for social protection due to CZS was viewed within the context of the start of the epidemic. Even before the etiology or associations were defined, the social fact of the births of children with microcephaly at numbers much higher than before was established and with this came an aggravation of poverty capable of negatively affecting the full development of these children.

The Rapid Action Strategy for Strengthening Healthcare and Social Protection for Children with Microcephaly was established through interministerial decree 405 of 15 March 2016⁴⁰ and through instructions for joint operations^{41,42}. This was an emergency activity to provide guidance for coordination between instruments and devices already present in the framework of Social Care policies and those of Health and Social Security, examples being an active search for cases, guidelines, forms of reception, referrals, the issuing of medical reports and instructions for proceedings.

This set of measures was established during the epidemic's critical period and was intended to speed up responses to issues such as insufficient income, severe poverty and social protection in the face of imminent increases in demand.

Pereira et al.⁴³ demonstrate that the number of BPC concessions for children up to 48 months of age with a microcephaly diagnosis was eight times higher in 2016 than the average annual benefits in the period from 2009, rising sharply in absolute numbers from 200 to 1603. The authors confirm that, in addition to this increase, the distribution of cases is consistent with the CZS epidemic, since 73.1% of benefits were granted in the Northeast Region.

The Brazilian State's first action was therefore aimed at regulating the activities of local agents, characterized as the "mobilization and adaptation of static rules to social facts"⁴⁴ (p. 84).

Subsequently, law 13301 of 27 June 2016⁴⁵, whose origin is MP 712 of January 2016⁴⁶, addresses health surveillance activities related to imminent danger of the transmission of Dengue, Chikungunya and Zika. Article 18 includes an extension to 180 days for maternity leave and wages for mothers of children affected by CZS, as well as a determination about granting the BPC to the affected children for a maximum of three years, called the Temporary BPC.

MP 712/2016⁴⁶ was also issued at a critical moment in the epidemic, although it did not address income transfer or any other social welfare or security benefit and was exclusively focused on health surveillance activities with an emphasis on health authority access to abandoned properties.

The BPC and the financial impact of CZS did not fall within the intended aims of MP 712/2016⁴⁶ and equally were not central to the 108 amendments proposed by members of parliament during the MP's debate. However, nine of these proposed amendments concern social policy areas proximate to social protection, that is: one about education, suggesting priority for affected children; seven related to extending maternity leave and wages or reducing the working day for those responsible for the children; and one proposed amendment about granting indemnity for moral damages and lifetime pensions for victims of Guillain-Barré Syndrome and Zika-associated microcephaly.

The emergence of themes related to education, care provided directly by families, with an emphasis on the maternal role, as well as labour rights and indemnity within the public debate of an MP about health surveillance constitute an attempt to introduce social policy issues and outline the public problem.

The BPC, and maternity leave and wages were incorporated into article 18 of Law 13301⁴⁵, whose amendment outlined the scope of health surveillance, therefore, despite the relevance of the themes, creating a legislative rider^(g). This is because its content was different from the MP from which it originated, thereby violating both due legislative process and the democratic principle, as understood by the Supreme Federal Court (STF) in its judgment of Direct Action of Unconstitutionality (ADI) 5127:

1. It violates the Constitution of the Republic, notably the democratic principle and due legislative process (arts. 1, section sole paragraph, section 2, section 5, and LIV, CRFB), the practice of insertion, through parliamentary amendment, during the legislative process of converting the provisional measure into law, of matters with a thematic content foreign to the original object of the provisional measure⁴⁸.

Despite article 4 of Resolution 1/2002^{49(h)} of the National Congress expressly vetoing the practice of legislative riders, article 18 of law 13301⁴⁵ addresses two social security themes within health surveillance regulation. However, article 18 is more representative in how it demonstrates negativity about comprehensive social protection and social security, which in themselves were not developed as public issues or policies related to CZS. In other words, despite the existence of the social fact, the issue did not reach the public arena as a problem worthy of a solution to be employed by the public authorities⁴⁴, rather it emerged as a mere legislative rider.

Furthermore, the BPC was treated as a solution that had found a problem⁵⁰, since article 18 reasserted what had already been defined in the Organic Law of Social Assistance¹⁶. By describing the benefit as temporary it was also redundant, and erred in establishing a restriction of three years, something that had not previously existed.

In the preamble (EMI 082/2019)⁵¹ of the third act related to this theme, MP 894/2019 takes precisely this issue of law 13301⁴⁵ as a central argument for its relevance and urgency, three years later, stating in paragraph ten that:

^(g) The expression "legislative rider" [*cauda legislativa or rabilongos* in Portuguese] refers to the inclusion of provisions having little connection with the Bill's subject matter and are intended not to draw attention to subjects thus included⁴⁷ (p. 134).

^(h) The regulatory text that deals with the procedures for processing MPs.



To access the temporary benefit, applicants must comply with the same rules as those of the regular BPC. In short, the only effective difference between the regular BPC and the temporary benefit, therefore, is that it imposes a three-year limit on the benefit. In practice, the temporary benefit was therefore not implemented⁵¹. (p. 4)

However, one element that is not explicit refers to the fact that children with CZS have already challenged initial expectations and are living beyond three years of age, throwing light on “the precarious nature of the coordinated intersectoral network ready to receive them”⁵² (p. 2).

The justification for the need to correct the previous regulation addresses the theme of social protection related to CZS and places elements referring to Social Welfare Policy at the core of the MP. The new act eliminates article 18 of law 13301⁴⁵ as a solution to the problem in question, but establishes a lifetime pension as an *indemnifiable* act only for beneficiaries of the BPC and in order to replace it.

The establishment of a lifetime pension entails State recognition of the long-term impact of a phenomenon, providing reparation for an omission or criminal act. In recent Brazilian history, health-related cases of *indemnifiable* lifetime pensions are concerned with health surveillance and human rights violations, such as those related to Thalidomide Syndrome (Law 7070 / 82), the deaths of victims of haemodialysis in Caruaru (Law 9422 / 96), victims of the Cesium-137 accident in Goiânia (Law 9425 / 96) and people with leprosy subjected to compulsory hospitalization and treatment (Law 11520 / 07).

By presenting previous pensions as part of the justification for the lifetime pension within the scope of MP 894, this act calls on the State to assume indemnity in the face of the long-term impact of this serious health problem. In this sense, it requires indemnity lawsuits on the part of the beneficiaries against the State to be withdrawn⁽ⁱ⁾, putting the onus on the budgetary plan known as the Federal Government’s Indemnity and Special Pensions, without committing significant expenditure, since one benefit is replaced with another.

MP 894/2019² therefore referred to two distinct problems, the transfer of income through the qualified BPC, based on an error in the previous regulation, and the pension as an act of indemnity related to a serious public health problem. However, it only presented a sole solution, the replacement of the BPC with the lifetime pension. This single act disregarded the transfer of income as part of the social protection for PwD living in poverty already established in current Social Welfare policy and weakened the function of indemnity related to a public health problem of significant magnitude, by restricting access to the same BPC beneficiaries.

One justification for this was a lack of available funds for the State to fully exercise its indemnity function. Another claim was that, by replacing the BPC with a pension, should a family member enter the world of work and their income therefore rise, the

⁽ⁱ⁾ This requirement increases the likelihood of inequity, since families with an income above the BPC cut-off point are not entitled to the pension and may file for damages.

family would not risk losing the benefit. It is evident, however, that one of the central problems of the BPC, the low income cut-off point, was not addressed in this response to CZS, nor was the public issue of the relationship between poverty and disability.

In 1996, a Draft Bill aimed to change the per capita family income required to access the BPC from a quarter to half a minimum wage⁵³. In March 2020, law 13981⁵⁴ was published with this alteration, however the STF upheld Claim of Non-Compliance with a Fundamental Precept 662⁵⁵ with a request for a precautionary measure proposed by the President of the Republic preventing the law from being enforced, on the grounds that it created expenditure without providing an estimate of its budgetary and financial impact.

We can see that the flawed debate about poverty and disability in Brazilian society is aligned to a trend for reversals to social protection as a citizen's right and the duty of the State, transferring responsibility for support back onto the citizens themselves¹³.

In terms of procedure, MP 894 of 4 September 2019² was sent to the National Congress on 5 October 2019 and, using the prerogative of extension, its deadline for deliberation terminated in February 2020. During this period, a Mixed Commission (Chamber and Senate) was established, whose work culminated in the MP being converted into law 13895⁵⁶ in April 2020.

Three public hearings were held and 144 amendments to the final text examined, of which five were accepted (one totally and four partially), including alterations correcting the name of the pathology, from microcephaly to CZS, and changes to the beneficiaries' birth dates, from between 1 January 2015 and 31 December 2018, to between 1 January 2015 and 31 December 2019.

Amendments that were not accepted referred to the preservation of the pillars of unconditional cash transfers to the affected children, other possibilities for increased expenditure, such as maintaining the BPC in addition to the indemnity pension, and increased access to the lifetime pension. Although the justification in the Commission's plenary debates and final report recognized the existence of matters related to the economic impact of CZS and the BPC income cut-off point, the discourse about fiscal austerity was restated; a discourse that has gained ground internationally since the 1990s.

Final considerations

Due to its magnitude, CZS required rapid scientific and state responses, with success in establishing the association with the agent, vector and modes of transmission, in the development of technology for diagnosis and prevention, as well as in promoting research and professional training^{57,58}. In the broadest sense, it constituted:

a total social fact [...] which reflects a multiplicity of facts and meanings, ranging from the relationship established with the mosquito (a non-human being) to one of the most basic human acts, birth⁵⁹. (p.225)



Reflecting concerns about child development, particularly as it intersects with the complex relationship between poverty and disability.

However, insufficient income, vulnerability and the social risks of children with CZS have not found a solution at State level. Despite increased demand for the BPC, and other evidence of the poverty of the children affected, state action has ranged from redundancy to the denial of rights, while the financial impact of CZS has not been prioritized through the justification of fiscal austerity.

By replacing the BPC with a lifetime pension, MP 894/2019² adopted a negative approach to the Brazilian State's constitutional duty to provide decent living conditions for PwD through unconditional cash transfer, as laid down in the 1988 Constitution¹⁵. It promoted a rupture with the first Brazilian framework for comprehensive social protection, the BPC, at a time when emancipatory gains for PwD are under threat.

Authors' contributions

All authors actively participated in all stages of preparing the manuscript.

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Conflict of interest

The authors have no conflict of interest to declare.

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Desde 2015, a Síndrome Congênita do *Zika* Vírus (SCZV) marca o cenário brasileiro, extrapolando o campo da Saúde Pública com demandas da proteção social. Considerando a intersecção entre pobreza, deficiência e marcos da seguridade social, examina-se a Medida Provisória 894, que prevê renda mensal vitalícia para as crianças acometidas. Com o objetivo discutir o instrumento à luz dos marcos da seguridade social no recorte da transferência de renda não condicionada para as pessoas com deficiência (PcD) no Brasil, realizou-se um estudo qualitativo mediante análise de documentos públicos e revisão de literatura. As respostas estatais não produziram impacto na insuficiência de renda porque voltaram-se inicialmente para atender à situação emergencial, recorrendo às políticas preexistentes, e culminaram na substituição entre modalidades de transferência de renda – o Benefício de Prestação Continuada para Pensão Vitalícia –, revelando fragilização da proteção social integral.

Palavras-chave: Deficiência. Proteção social. Síndrome Congênita do *Zika* vírus.

Desde 2015 el Síndrome Congénito del *Zika* Vírus (SCZV) marca el escenario brasileño, extrapolando el campo de la salud pública con demandas de la protección social. Considerando la intersección entre pobreza, discapacidad y marcos de la seguridad social, se examina la Medida Provisional 894 que prevé renta mensual vitalicia para los niños afectados. Con el objetivo de discutir el instrumento a la luz de los marcos de la seguridad social en el recorte de la transferencia de renta no condicionada para las Personas con Discapacidad (PcD) en Brasil, se realizó un estudio cualitativo mediante análisis de documentos públicos y revisión de literatura. Las respuestas estatales no causaron impacto en la insuficiencia de renta porque inicialmente se enfocaron para atender la situación de emergencia recurriendo a las políticas preexistentes y que culminaron en la substitución entre modalidades de transferencia de renta, el Beneficio de Prestación Continua para Pensión Vitalicia, revelando la fragilización de la protección social integral.

Palabras clave: Deficiencia. Protección social. Síndrome congénito del zika virus.